

ASTHMA & ALLERGY

BULLETIN

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER • VOL. 26, No. 1

From the Executive Director

Dear Friends,

I hope that you are enjoying your summer. We remain busy at AAFA New England helping children, adults and families to manage their asthma and allergies. With our help, New Englanders can work and play however they choose. You can read how we helped Carla Uzzell's family when her child was diagnosed with food allergies. You'll also find the inspiring story of Danielle Ithier, our scholarship winner.

Asthma and allergies are life-threatening, serious diseases. Our mission is to educate individuals and those who care for them so they can enjoy healthy, productive lives. But we are serious also when we tell you that your donations and memberships are critical for us to continue to provide our educational programs, telephone consultation and training for nurses, child care providers and schools. Please support our ability to help your family and others by sending in your membership or donation today. We want to be here for you when you need us.

Elaine Erenrich Rosenburg
Executive Director

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Massachusetts Restaurants to Become Safer for People with Food Allergies

A new Massachusetts law will help increase awareness of food allergies in restaurants and encourage good communication between people with allergies and the restaurant staff.

Although the Food Allergy Awareness in Restaurants (FAAR) Act was signed into law in January, 2009, restaurants have until October 1 of this year to implement the first two major requirements of the law:

- A **poster** should be prominently displayed in the employee work area describing major food allergens, the health risks of food allergies, procedures to follow when a customer states that he or she has a food allergy, and emergency procedures to follow if a customer has an allergic reaction.

- A **notice** should appear on all printed menus and menu boards stating: *"Before placing your order, please inform your server if a person in your party has a food allergy."*

"This will be a good reminder to follow the practice we have long

been recommending as the first step in staying safe while eating out," says Sharon Schumack, Director of Education for AAFA New England.

By February, 2011 restaurants must implement the third important component of the law: **food allergen awareness training** for a staff member who will complete an approved video training program, be the designated "certified food protection manager," and train other employees in food allergy awareness.

"We are hopeful that these new requirements will encourage restaurants in Massachusetts to become more 'food allergy friendly,'" says Schumack. "But it is still vital that everyone with food allergies remain cautious about ingredients and food handling, make wise choices, and always be prepared with emergency medicine and an allergy action plan."

(See our website for other tips on eating out safely with food allergies.)

When you dine out with your family you probably discover that some restaurants are better than others at accommodating customers with food allergies. Rate your experiences at AllergyEats (www.AllergyEats.com), a new, interactive, peer-to-peer website that collects feedback from families like yours – helping the food allergy community find safe places to eat.



It takes less than a minute to report how well (or poorly) an establishment accommodated your special food requirements. And it's quick and easy to find an allergy-friendly restaurant based on other people's feedback.

AllergyEats lists over 600,000 restaurants, information on restaurants' menus, allergen lists, nutrition information, web links, directions and more. It has become the fastest-growing source for finding allergy-friendly restaurants, and depends on input from people like you!

Is it Possible to Be More Precise in Diagnosing Food Allergy?

Current diagnostic procedures, including both laboratory studies (ImmunoCAP/RASTs) and skin testing, are relatively imprecise in identifying sensitization to foods. As anyone with either a personal history of food allergy or with a child having food allergy has experienced, tests often seem to identify allergy to foods which may not be clinically relevant – that is, the foods do not actually cause a reaction.

The results of a “screening panel” often lead to more confusion, rather than providing helpful guidelines to the doctor and patient. This is because current testing only identifies the presence of IgE (the allergy factor) and not necessarily clinical sensitization. We know that this may be because the IgE could be directed either at allergenic or non-allergenic portions of the food protein.

Newer diagnostic procedures are being developed that may be more helpful in differentiating between

people who have “sensitization” and those who have true clinical “allergy” to a particular food.

A recent study has used a laboratory technique called “component-resolved diagnostics” or “microarray assays” to study this problem in peanut-sensitized individuals. A group of investigators from England and Sweden used this new technology to try to identify children who had true allergy to peanut versus those who were simply sensitized but were “tolerant,” meaning they could consume peanut without a reaction.

Approximately 1,000 children participated in their long-term study of food allergy. At eight years of age they were assessed for the presence of peanut allergy. By either prick testing or standard ImmunoCAP/RAST evaluation, 110 of these children were considered as being sensitized to peanut. Based on a variety of factors, such as finding out whether they had a history of having had a reaction to

peanuts and giving some an oral food challenge, the children were classified as either peanut allergic or peanut tolerant.

The investigators compared this information with the results of testing with the new technology (component-resolved diagnostics), and found the frequency with which children were misidentified was significantly decreased by using the newer diagnostic method. Nonetheless, even with this new technology, 10% of children continued to be misclassified.

Certainly, new technologies are essential to better identify individuals who truly have a food allergy! The component-resolved diagnostic procedure is at least a good step in this direction. Physicians, patients, and parents all look forward to more precision to guide the diagnosis and necessary dietary restrictions for people with food allergies.

Source: Nicolaou, N. et al. Allergy or tolerance in children sensitized to peanut: Prevalence and differentiation using component-resolved diagnostics. Journal of Allergy and Clinical Immunology, 125:191, 2010.



New Criteria for Classifying Asthma Could Improve Your Treatment

In the past, asthma was considered a more or less uniform condition. Differences between whether it began in childhood or adulthood and the severity and role of allergy were used to identify a person's type of asthma.

National asthma treatment guidelines introduced in the 1990's divided the condition by severity and persistence. This classification system, which is still evolving, has helped in directing treatment recommendations. For example, someone with “mild intermittent” symptoms has a different treatment plan than someone whose asthma is determined to be “moderate and persistent.”

Asthma is, however, a complex condition. Many investigators have attempted to further classify asthma using a wide variety of different measures.

In a recently published study, researchers used a large number of variables to classify the severity of asthma in 726 people, and identified five “clusters” of patients. The least severe was classified as Cluster I. These individuals experienced early onset of asthma in childhood, were more likely allergic, had normal lung functions, and required less asthma treatment. In contrast, the most severe were in Cluster V. These individuals

developed asthma as adults, had a longer duration of asthma, were less likely to be allergic, and had abnormal lung function. They also required more aggressive asthma treatment and often did not fully respond to this therapy.

Of all the variables they used to classify the asthma of people in the study, the most important were age of onset and pulmonary functions before and after bronchodilator. Obesity, particularly in females, was most prominent in the medium-severity Cluster III.

(continued on next page)

GROWING UP WITH ASTHMA OR SEVERE ALLERGIES

How do teens from around New England handle social and school situations involving their asthma and allergies? How do they advocate for themselves, maintain sound treatment plans, or deal with social pressures? Over sixty high school seniors responded to these questions as part of AAFA New England's annual scholarship competition.

A \$250 scholarship was awarded to **Danielle Ithier of Hooksett, New Hampshire**. Eleven outstanding students were awarded Honorable Mention. These inspiring teens were selected based on their compelling essays on "Overcoming Obstacles to Managing Asthma or Severe Allergies as a Teen," excellent academic records; and an amazing array of activities and community service commitments. A booklet of the winning essays is available from AAFA New England.

"I was diagnosed with asthma in fourth grade and life has been very different ever since," says Danielle, a straight "A" student ranked first in her high school graduating class. Danielle has received an array of awards for

her academic achievements, mostly in math and science. In addition to her work on the school's robotics and math teams, she played varsity soccer all through high school and was Captain during her senior year.

"Since finding out I had asthma I have worked with my doctors to create a management plan," wrote Danielle in



her winning essay for the AAFA NE scholarship. "As outlined in the plan, I need to take controller medications daily, carry an inhaler at all times, and keep track of peak flows when I am not feeling well. After learning about the different

triggers to my asthma – changes in weather, extreme cold, smoke, and mold – I have learned to avoid them when possible."

In describing some of the challenges she has faced, Danielle recalled an invitation to a friend's birthday party where there was going to be a bonfire. "I had to decline, because I was already having difficulty with my

asthma," she said, "and I knew that by going to the party it could be further aggravated by the smoke. I called my friend and we planned a different night to celebrate."

Despite her mature and responsible approach, Danielle still suffers from occasional asthma flare-ups that require her to miss school. She and her parents worked with a school administrator to develop a "504 plan" to accommodate her medical condition, and works closely with her teachers keep up with the work she misses when absent.

Danielle plans to attend Harvard University in the fall.

Congratulations to the following students who were awarded HONORABLE MENTION

Samantha Ahern, W. Bridgewater, MA
Rachel Beaudry, Henniker, NH
Sarah Cool, Naugatuck, CT
Timothy Casey, Longmeadow, MA
Alexandra Craft, Hyde Park, MA
Aimee Donaruma, Hampden, MA
Danielle Foraker, Hope Valley, RI
McKenzie Mann, E. Thetford, VT
Rebecca McLean, Birch Harbor, ME
Chelsea Paholski, Ivoryton, CT
Madeline Walsh, Manchester, NH

RESEARCH UPDATE (continued from page 2)

An editorial in the medical journal that published the study suggests that this classification system should be considered for future studies on asthma pathophysiology and treatment. The author speculated that this approach will "uncover unsuspected mechanisms of disease and increase the likelihood that we can ultimately provide personalized programs of care for our patients with asthma."

In another study, researchers measured exhaled nitric oxide, a "marker" or indication of airway inflammation. They found it was possible to classify the severity of asthma by measuring this "biomarker," and identify indi-

viduals with severe asthma and the highest degree of airway inflammation and reactivity.

Up to a third of those with asthma do not respond fully even to inhaled steroid medications, the most potent treatment we currently have available. These and other new insights into the classification and causes of asthma may lead to improvements in treatment, and better control of your asthma.

Sources:

Moore, W.C. et al. Identification of asthma phenotypes using cluster analysis in the Severe Asthma Research Program. *American Review of Respiratory and Critical Care Medicine*, 181:315, 2010.

Fahey, J.V. Identifying clinical phenotypes of asthma: Steps in the right direction. *American Review of Respiratory and Critical Care Medicine*, 181:296, 2010.

Dweik, R.A., et al. Use of exhaled nitric oxide measurement to identify a reactive, at-risk phenotype among patients with asthma. *American Review of Respiratory and Critical Care Medicine*, 181:1033, 2010.

Frank J. Twarog, M.D., Ph.D., is an allergist in Brookline and Concord, MA, and serves as President of the Asthma and Allergy Foundation of America, New England Chapter. He is a Clinical Professor at Harvard Medical School.



May 2, 2010 was a magical evening on Boston Harbor, when members and friends of AAFA New England gathered on board The Majesty for our successful annual gala fundraiser.

Many thanks to the sponsors, donors, and volunteers who helped make this benefit a success!

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Michele Abu Carrick *(center)*
& Robyn Nasuti, *(right)*
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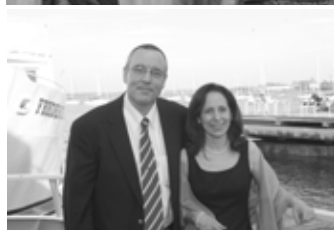
Ruth Lovett Smith *(left)*
Auction Chair
Bonnie O'Connor, Heather Mehra
& Tricia Rowe *(not pictured)*



SPECIAL THANKS to Robert Ruscansky Photography for these great photos, and Lisa and Jim Engelbrecht, Creative Sparks Design, for designing a beautiful invitation.

Proceeds from the annual Breath of Spring gala support AAFA New England's educational programs, public awareness, advocacy, and support for research to help people live with allergies and asthma.

We have tried our best to acknowledge everyone. If we have inadvertently missed you, please accept our apologies and heartfelt thanks for your generosity.



Fabulous Auction items included theater and sports tickets and gift certificates for restaurants and salons. For a complete list of auction donors, see our website: www.asthmaandallergies.org. Please patronize these generous businesses.



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Jessica is Ready for Pre-school – With the Help of AAFA New England

by **Carla Uzzell**

When my daughter, Jessica, was 17 months old she found a cashew on our kitchen floor and put it in her mouth. Immediately, she began gasping for breath, her lips swelled and she tried to cry. We went straight to the ER on that snowy evening in February, 2008. I remember every single detail of that night as if it were yesterday.

Until the moment when she was looking to me for help, unable to get a breath, I had no idea my baby had life-threatening food allergies.

For many weeks after that terrifying night, I was afraid: afraid to leave our house with my baby, afraid to trust someone else to care for her, afraid to feed her.

Until Jessica's first anaphylactic reaction, I had known parenting had its challenges. I was ready and willing to handle anything. But this caught me by surprise! I felt completely unprepared to handle raising a child with life-threatening food allergies.

Seeing how broken I was, my mom encouraged me to reach out to others who are also raising children with food allergies. Soon after, I found out about the New England Chapter of the Asthma and Allergy Foundation of America.

Being a member of AAFA New England is very important to me as I raise my daughter to be strong and safe while living with food allergies. I look forward to attending the meetings that AAFA NE organizes. I read the newsletters that AAFA distributes. Through this support system, I have learned a lot about what my daughter can and will do in life, despite having food allergies. I am learning ways to teach her to be prepared, yet not paranoid.



Jessica is an amazing little girl, who happens to have life-threatening food allergies. At three-and-a-half years old, she proudly will show others her medical alert bracelet. She instinctually will ask "Is this safe for me?" when offered food when we are out and about. She knows never to eat anything unless the ingredients have been read and reread. This isn't the life I had planned for my healthy little girl, but this is her reality. Raising a cautious child goes along with living with food allergies.

I know I won't be with Jessica everywhere she goes, but I will be attending AAFA New England meetings and reading its newsletters every chance I get. With the knowledge I gain from AAFA NE, I can help make Jessica's life experiences safe! Pre-school starts in the fall. She is excited and ready! I am excited and nervous. With the support that I have found from AAFA New England I am gearing up for this next chapter in Jessica's life.

Carla Uzzell is mom to Jessica who is 3 1/2 years old and Alison who is 2 years old. She is a former elementary school teacher, and is currently a stay-at-home mom and tutor of elementary students. She and her husband Mark and their two daughters live in Waltham, MA.

We can help YOU and your family, also!

Become a member today, so we can continue to provide the tools and confidence you need.

See page 7 for a membership form, join on-line at www.asthmaandallergies.org, or call the office to use a credit card (781-444-7778).

Food Allergy Leader is New AAFA New England Board Member

As the mother of a child with multiple life-threatening food allergies as well as environmental allergies, Ruth Lovett Smith of Harvard, MA realized how difficult it was to find appropriate and safe products, information and support. She has quickly emerged as a leader in the food allergy community, and we are delighted to welcome her as a new member of the Board of Directors of AAFA New England.

Ruth has served as the co-leader of our Nashoba Valley Asthma and Allergy Educational Support Group, chaired the Auction Committee for this year's Breath of

Spring Gala (see page 4), and is currently helping with our Facebook page.

Ruth is the founder of Best Allergy Sites, an online directory and resource guide, and co-creator of Food Allergy Twitter Parties, on-line educational events that bring together food allergy businesses, experts, and families. She is a freelance writer on food allergies, parenting, special needs, organic gardening, green living and healthy eating. Her article about advocating for individualized school health care plans for students with food allergies was in the Winter, 2010 issue of this newsletter. (Contact us if you would like a copy).

Bike Ride Benefits AAFA New England Programs

A small group of brave bicycle riders endured thunder, rain and traffic on one of the stormiest Saturdays of the spring to participate in a 25-mile "Fun Ride" to benefit AAFA New England. It was organized by Mark Westberg of Hudson, MA to help raise awareness about asthma and raise funds for AAFA New England's educational programs.



Mark Westberg, organizer of "Fun Ride" for AAFA New England

Even though it wasn't a great day to bike around Wachusett Reservoir, Mark's friends and family contributed generously, for which we are very, very grateful.

Everyone is hoping that the weather will cooperate next year, so they can enjoy the barbecue and bocce tournament that are planned for after the bike ride. Bicyclists: let us know if you would like to be included!

Asthma is a serious illness!

Because so many people have asthma, it is easy to think of it as commonplace, and therefore not very serious. But approximately 4,000 people in the USA die each year as a result of poorly-controlled asthma.

AAFA New England provides the information that people need to manage their asthma and stay healthy, but we can't do it without much-needed funding. Make your donation or join today, so we can keep saving lives.

ASTHMA & ALLERGY BULLETIN

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The Asthma and Allergy Foundation of America, New England Chapter, is dedicated to helping people with asthma and allergic diseases, and those who care for them, through education, support for research and an array of services.

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received in memory of:**

Edward L. Conley

Robert Forest

Filomena Mattia

Marc Osipoff

Shawn Stanwood

To contribute a memorial gift or tribute in honor of a special person or a birthday or other event, please send a check payable to AAFA New England.

MC/VISA accepted by phone, mail, or on our website: www.asthmaandallergies.org. Please include the name of the person being honored or memorialized, and let us know who to notify of your donation.

Young Philanthropists Raise Awareness and Support for Asthma and Allergy Education

The children in the Nasuti family are learning how to be philanthropists at a young age. Following in the footsteps of their generous mother Robyn,



Co-Chair of this year's Breath of Spring Gala (see page 4), ten-year-old Taylor Marie Nasuti and her siblings Nicholas (age 5) and Brett (age 12) organized a community

fundraiser to benefit AAFA New England.

Taylor met with the manager of Papa Gino's of Milford, MA and filled out the forms to apply for the company's donations program. She and her brothers prepared a flyer and distributed it through school and to family and friends, inviting them to participate.

At Taylor's request, we helped by sending an e-mail announcement

to our contacts in the area. Twenty percent of the pre-tax sales from everyone who brought the flyer to the restaurant on the day of the fundraiser were donated to AAFA New England.

"There was very little work involved," said Robyn, "and I really believe that teaching children at a young age to help others helps define the well-rounded individuals they will become. Start small and age-appropriate, and you will be surprised how much kids enjoy the experience."

Here are some other ideas Robyn suggests for how to help your children develop a philanthropic nature as well as help support AAFA New England's programs:

- Host a lemonade stand and advertise that the proceeds (or a portion) will go to benefit the thousands of people living with food allergies and asthma.
- Sponsor an AAFA NE Read-a-Thon at your child's school. Kids can make posters and get their friends involved. (Contact us for details.)

- Work with a local restaurant that offers to donate a portion of the proceeds from sales on a designated date. (Several chains have such programs.)
- Have a "wear a hat" or "chew gum" day at school (with principal's approval) and donate the proceeds to AAFA New England.

Would your family like to organize a community fundraiser to raise awareness as well as raise funds for AAFA New England? *Let us know how we can help, and send us a photo for our next newsletter!*

Leaving for college this fall?

Before you finish packing and head to campus, check out our tips for meeting the challenges of asthma and allergies at college.

You'll find it at:

www.asthmaandallergies.org



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